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ABSTRACT

This final report describes the activities and accomplishments of a 3-year model demonstration early intervention network serving infants who are deaf-blind and their families. The primary goal of the project was to build the capacity of early intervention programs. Sixteen early intervention programs participated in at least one component of the project and nine programs participated in a majority of project activities. Project activities involved identifying, developing, and documenting effective early intervention practices with infants whose multiple disabilities include both vision and hearing loss and their families. Project objectives were accomplished through such activities as: family/professional focus group meetings, program self-reviews, program development plans, interdisciplinary focus group meetings, a supervisory focus group meeting, workshops, follow-up consultation, and materials development. The project produced a manual on effective practices in early intervention with this population and four videotapes which have been made commercially available: "Making the Most of Early Communication," "What Can Baby Hear? Auditory Tests and Interventions for Infants with Multiple Disabilities," "What Can Baby See? Vision Tests and Interventions for Infants with Multiple Disabilities," and "Vision Tests for Infants." Individual sections of the report cover the project s goals and objectives, conceptual framework, model and participants, activities, problems and departures from the original plan, evaluation findings, and impact. (DB)

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EARLY INTERVENTION MODEL DEMONSTRATION NETWORK FOR INFANTS WHO ARE DEAF-BLIND AND THEIR FAMILIES

Final Report

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February 28, 1997

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Abstract

The *Model Demonstration Early Intervention Network serving Infants who are Deaf-Blind and their Families* was a three year project of California State University, Northridge funded by the U.S. Department of Education from October 1, 1993 to February 28, 1997. The project demonstrated a unique collaboration between the Department of Special Education, California State University, Northridge; California Deaf-Blind Services, State Department of Education; and public and private agencies serving infants who are deaf-blind and their families.

The primary goal of the project was to build the capacity of early intervention programs to serve infants who are deaf-blind and their families. Sixteen early intervention programs participated in at least one major component of the project and nine programs participated in a majority of project activities. Project activities involved identifying, developing, and documenting effective early intervention practices with infants whose multiple disabilities include both vision and hearing loss and their families. Project objectives were accomplished through a series of activities: family/professional focus group meetings, program self reviews, program development plans, interdisciplinary focus group meetings, a supervisory focus group meeting, workshops, follow up consultation, and the development of materials.

All deaf-blind projects (307.11) in each state received copies of the products developed by the project. In addition, programs participating in the project and contributors to the products received copies. The project produced a manual

entitled *Effective practices in early intervention. Infants whose multiple disabilities include vision and hearing loss.* Four videotapes were developed: *Making the most of early communication; What can baby hear? Auditory tests and interventions for infants with multiple disabilities; What can baby see? Vision tests and interventions for infants with multiple disabilities*; and *Vision tests for infants.* Booklets have been developed to accompany each tape and arrangements have been made for dissemination with commercial publishers. Paul H. Brookes Publishing to disseminate *What can baby hear?* and AFB Press will disseminate the other three videos.

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Goal and Objectives

The primary goal of the project was to build the capacity of early intervention programs serving infants who are deaf-blind and their families. Project activities involved identifying, developing, and documenting effective early intervention practices with infants whose multiple disabilities include both vision and hearing loss. Specifically, the project focused on five objectives:

1. To establish and facilitate a network of early intervention programs as Model Demonstration Sites serving infants and toddlers who are deaf-blind and their families in southern California.

2. To identify and document effective practices in the network of Model Demonstration Sites which meet Part H requirements.

3. To develop and demonstrate transdisciplinary and interagency service delivery approaches.

4. To develop and demonstrate early intervention strategies which are family-focused and culturally-responsive.

5. To document and disseminate materials and other products which enable replication of effective strategies and quality practices in serving infants and toddlers who are deaf-blind and their families in early intervention programs in California and across the nation.

Conceptual Framework for the Project

The project was designed for active involvement of participating programs in guiding project activities. First, seven early intervention programs were represented

by a family/professional team at focus group meetings. These meetings identified overall effective practices and needed areas of program development in serving infants who are deaf-blind and their families. Next, five programs elected to participate in a Program Self Review to identify their effective practices and areas to be developed. The project focused on providing technical assistance to assist program development in identified areas of need and developed written and videotape materials to document effective practices.

Description of the Model and Participants

Project goals were accomplished through a series of activities: family/professional focus group meetings, program self reviews, program development plans, interdisciplinary focus group meetings, a supervisory focus group meeting, workshops, follow up consultation, and the development of videos and a manual documenting effective practices. The following 9 programs were involved in major components in all three years of the project:

- Off to a Good Start Program, Blind Babies Foundation, San Francisco
- Preschool Program, Blind Children's Learning Center, Santa Ana
- Infant-Family Program, Foundation for the Junior Blind, Los Angeles
- Infant Deaf and Hard of Hearing Program, Los Angeles County Office of Education
- Deaf and Hard of Hearing Infant Program, Los Angeles Unified School District
- PIVIT (Parents and Infants with Visual Impairment Together), Los Angeles Unified

School District

- Early Start Program, Marin County Office of Education, San Rafael
- Infant Program, West End Selpa Early Start, San Bernardino County Office of Education, Ontario
- Deaf Special Needs Program, San Diego Unified School District

An additional 7 early intervention programs participated in at least one major component of the project:

- Kern County Regional Center
- Bakersfield Infant Program
- Centro de Ninos y Padres
- CHIME Infant Program
- Atwater Park Center Infant Program
- Easter Seals Infant Program
- Orange County Program for Visual Impairment

Project Activities

The project conducted family/professional focus group meetings and program self reviews to identify primary program needs and to reveal effective practices. The following programs participated in the family/professional focus group meetings:

- Off to a Good Start Program, Blind Babies Foundation, San Francisco
- Preschool Program, Blind Children's Learning Center, Santa Ana

- PIVIT (Parents and Infants with Visual Impairment Together), Los Angeles Unified School District

- Early Start Program, Marin County Office of Education, San Rafael

- Infant Program, West End Selpa Early Start, San Bernardino County Office of Education, Ontario

- Deaf Special Needs Program, San Diego Unified School District

The family/professional focus group meetings were composed of teams of direct service providers and parents of children who are deaf-blind. A total of 15 family representatives and 15 professionals participated in these meetings plus three educational specialist/family specialist teams from California Deaf-Blind Services who assisted project staff in facilitating and recording group input.

The following programs requested Program Self Reviews:

- Off to a Good Start Program, Blind Babies Foundation, San Francisco

- Preschool Program, Blind Children's Learning Center, Santa Ana

- PIVIT (Parents and Infants with Visual Impairment Together), Los Angeles Unified School District

- Infant Program, West End Selpa Early Start, San Bernardino County Office of Education, Ontario

The Program Self Reviews involved committees of administrators, direct service personnel, and families. These reviews were facilitated and recorded by the project through a family/professional team of consultants or staff of California

Deaf-Blind Services. Program Self Reviews resulted in the identification of effective practices and in areas of program development needed to serve infants who are deaf-blind and their families more effectively. Frequently selected areas for program development included:

- Indepth training in a variety of early intervention strategies and curricula for infants with multiple disabilities/vision and hearing loss
- Implementation of functional vision and hearing screenings within the program model
- Increased skills in communication interventions for infants and toddlers who are deaf-blind
- Increased collaboration with other agencies serving infants with disabilities in the community
- Increased knowledge of transition options and support for families during this process
- Development of a formal evaluation process for families to evaluate program services

These identified areas for program development were addressed through a series of workshops, follow-up meetings, and onsite technical assistance visits. As a result of project efforts, programs increased their own awareness of the range of infants who fall under the "deaf-blind" label. The functional vision and hearing screenings resulted in increased referrals for audiological and ophthalmological

evaluations and in more consistent follow-up upon diagnosis and appropriate interventions.

In 1993-1994, four core early intervention programs (PIVIT, West End Early Start, Foundation for the Junior Blind, and Blind Children's Learning Center) involved in the project served a total of 25 infants whose multiple disabilities included vision and hearing loss and their families. In 1995-1996, four core early intervention programs(Blind Babies Foundation, Blind Children's Learning Center, Foundation for the Junior Blind, and West End Early Start served a total of 46 infants who are deaf-blind and their families. The 12 other early intervention programs who participated in the project served between 1 and 8 infants whose multiple disabilities include vision and hearing loss during the three year project.

Program self reviews and focus group meetings revealed a primary need for inservice training and materials on beginning communication strategies, audiological assessment and interventions, and vision tests and interventions for infants. In general, family members wanted materials that could help staff work with their infants more effectively. Both professionals and family members requested strategies for beginning communication particularly with infants who have significant motor and cognitive delays in addition to vision and hearing loss.

Early intervention personnel requested information not only for beginning professionals, but also for those with significant training and experience in vision impairment or hearing loss, particularly on recent developments in audiological and

vision tests for infants. The project addressed identified training needs through a series of workshops, onsite consultation, and the development of videos, and a project manual.

Inservice workshops included:

11/18/94- *Identifying and developing quality indicators of early intervention programs*, N = 8 supervisory staff.

7/22/94 - *Enhancing sensory and communicative behaviors in infants with multiple disabilities/vision and hearing loss: Intervention plans*. N = 51 early intervention staff from a variety of disciplines (child development, early childhood special education, visual impairment, deafness, occupational therapy) and parents of infants who are deaf-blind.

7/23/94 - *Enhancing sensory and communicative behaviors in infants with multiple disabilities/vision and hearing loss: Functional vision and hearing assessments and interventions*, N = 49 early intervention staff from different disciplines (child development, early childhood special education, visual impairment, deafness, occupational therapy) and parents of infants who are deaf-blind.

1/6/95 - *Identifying and developing quality indicators of early intervention programs* follow up meeting, N = 10 supervisory staff.

1/7/95 - *Meeting the intervention needs of infants and toddlers with multiple disabilities: A focus on hearing loss* follow-up meeting, N = 28 early intervention staff, N = 28 (child development, early childhood special education, and visual

impairment).

6/9/95 - *Understanding and encouraging communication with infants whose multiple disabilities include both vision and hearing loss: Assessment strategies* N = 61 early intervention staff from several disciplines (child development, early childhood special education, visual impairment, deafness).

6/10/95 - *Understanding and encouraging communication with infants whose multiple disabilities include both vision and hearing loss: Developing and implementing interventions*, N = 61 early interventionist staff from several disciplines (child development, early childhood special education, visual impairment, deafness).

10/6/95 - *Meeting the intervention needs of infants with multiple disabilities/vision and hearing loss: Functional hearing screening and interventions*, N = 60 early intervention program staff from a variety of disciplines (nursing, child development, early childhood special education, visual impairment, deafness, severe disabilities).

10/7/95 - *Understanding electrophysiological audiological evaluation of infants with multiple disabilities*, N = 15 (nursing, child development, early childhood special education, visual impairment).

11/13/95 - *Meeting the intervention needs of infants and toddlers with multiple disabilities: Functional vision screening and interventions*, N = 51 (nursing, early childhood special education, visual impairment, deafness, severe disabilities).

6/7/96 -6/8/96 - *Effective strategies for working with infants whose multiple*

disabilities include vision and hearing loss and their families, N = 30 (early childhood special education, visual impairment, deafness).

9/21/96 - *Transitioning young children with severe disabilities and multiple impairments into typical preschool environments*, N = 30 (family members, social workers and early interventionists with backgrounds in child development, early childhood special education or visual impairment).

Problems and Departures from the Original Planned Objectives and Activities

There were no significant departures from the original planned objectives although a different focus than planned had to be taken in some activities. A primary challenge was the lack of trained early interventionists with specialized training specifically in the area of dual sensory impairments. California does not have certification in the area of deaf-blind. In school district early intervention programs, infants whose multiple disabilities include vision and hearing loss may be served by a teacher certified in the area of visual impairment, hearing loss, severe disabilities, early childhood special education. In early intervention programs of private agencies, there are no personnel standards regarding certification. Although the majority of early intervention staff in participating early intervention programs were trained in the areas of visual impairment or hearing loss or severe disabilities or early childhood special education, there were some early intervention staff whose primary professional background was a child development undergraduate major. When the original proposal was being written in 1993, five programs were

identified as potential model demonstration sites because of their participation in a six-day INSITE training course on working with infants who are deaf-blind in 1992. However, once this project was funded and the program self reviews were conducted, all 5 programs required technical assistance in building their capacity to serve infants who are deaf-blind and their families. None of the programs demonstrated effective practices in all three key intervention areas, i.e., functional vision assessment and meaningful interventions; functional hearing assessment and meaningful interventions; and facilitating beginning communication development with infants with multiple disabilities/vision and hearing loss. Some programs demonstrated effective practices in the area of functional vision or hearing assessment and interventions but not in both areas of sensory impairment. All of the programs asked for assistance with developing communication strategies for preverbal infants with significant disabilities and vision and hearing loss. Thus the original plan to develop a mentor network of programs as a state resource and support visits by other early interventionists to participating programs could not be implemented. Instead, the project focused on supporting collegial support and interagency networking among participating programs. In addition, the project documented effective practices by videotaping across a number of programs to support early communication interventions and vision and hearing assessment and related interventions.

Another challenge was the lack of an established transdisciplinary or even

interdisciplinary approach within each participating program. The current status of the multidisciplinary intervention model being used by most programs influenced project activities in cross disciplinary inservice training and focus group meetings. In this way, the project developed and facilitated interagency and interdisciplinary approaches.

Evaluation Findings

Objective # 1. To establish and facilitate a network of early intervention programs as Model Demonstration Sites serving infants and toddlers who are deaf-blind and their families in southern California.

This objective was accomplished in that a network of early intervention programs was established. The project facilitated the development of collegial support across participating programs. Participating early intervention programs have demonstrated increased capacity in serving infants who are deaf-blind and their families by developing staff competency in conducting functional hearing and vision screenings and by developing meaningful interventions that support early communication development in infants with multiple disabilities/vision and hearing loss.

Objective # 2. To identify and document effective practices in the network of Model Demonstration Sites which meet Part H requirements.

This objective was accomplished through the implementation of a Program Self Review process. Effective practices were documented in the videotapes developed

by the project and in the project manual.

Objective # 3. To develop and demonstrate transdisciplinary and interagency service delivery approaches.

This objective was partially accomplished. A primary challenge was the lack of an established transdisciplinary or even interdisciplinary approach within each program. Inservice training activities involved early interventionists from a variety of disciplines. In addition, two focus group meetings were conducted with representatives from primary disciplines and participating programs to develop strategies for integrating objectives from different disciplines across an infant's typical routine. These strategies are documented in the project manual.

Objective # 4. To develop and demonstrate early intervention strategies which are family-focused and culturally-responsive.

This objective was accomplished in that early intervention strategies identified as effective and documented by the project were family-focused and culturally-responsive. Examples of these strategies are shown in the video and demonstrated in the manual.

Objective # 5. To document and disseminate materials and other products which enable replication of effective strategies and quality practices in serving infants and toddlers who are deaf-blind and their families in early intervention programs in California and across the nation.

This objective was clearly accomplished as demonstrated in the products that have

been developed and disseminated widely by the project (see next section). In addition, arrangements have been made with commercial publishers to disseminate materials after the end of the project.

Each project activity was evaluated by participant satisfaction and follow-up on action plans. Inservice training workshops received very high participant ratings on a 5 point scale with 5 as excellent, very helpful, and clearly presented. Overall ratings for helpfulness of content ranged from a mean of 4.90 to 5, clarity of presentation ranged from a mean of 4.25 to 5 and organization of the training ranged from a mean of 4.10 to 5.

Four videos were developed during the three year project:

Making the most of early communication was completed in August 1995. The project disseminated 100 closed captioned complimentary copies and a rough draft of a discussion guide to 307.11 projects, other deaf-blind projects, inservice and preservice training, early intervention programs. As a result of this dissemination, feedback was received from 437 individuals representing 19 states- Alaska, Arizona, California, Florida, Hawaii, Indiana, Kansas, Missouri, Nevada, New Jersey, New Mexico, New York, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, and Utah. Responses were very positive regarding the organization of the key ideas, simulations of vision and hearing loss, demonstration of interaction strategies, and heterogeneity of infants, toddlers and preschoolers and families represented. The draft discussion guide received mixed reviews and

the format was revised and content expanded based on this feedback. The project received requests for this video so 100 more copies were made and distributed at cost.

What can baby hear? Auditory tests and interventions for infants with multiple disabilities was completed in February 1996. The project disseminated 100 closed captioned complimentary copies to 307.11 projects, other deaf-blind projects, inservice and preservice training, early intervention programs. As a result of this dissemination, feedback was received from 106 individuals representing 12 states - Alaska, California, Connecticut, Illinois, Kansas, Louisiana, Missouri, Nevada, Rhode Island, New York, Utah, and Vermont. Responses were very positive regarding the clear explanation and demonstration of audiological tests, the parent interview, functional screening observations and encouraging the use of hearing aids. Feedback requested the development of a discussion guide and provided suggestions for content.

What can baby see? Vision tests and interventions for infants with multiple disabilities was completed in September 1996. The project disseminated 100 closed captioned complimentary copies to 307.11 projects, other deaf-blind projects, inservice and preservice training, early intervention programs. As a result of this dissemination, feedback was received from 68 individuals representing 11 states - Arizona, California, Kansas, Missouri, New York, North Dakota, Pennsylvania, South Carolina, Wisconsin, Utah and Vermont. Responses were very

positive about the overview of vision tests, use of corrective lenses, gathering information from families and their perspectives. Feedback indicated the need for a discussion guide and suggestions for content was provided.

Vision tests for infants was completed in February 1997.The project disseminated 75 closed captioned complimentary copies to 307.11 projects, other deaf-blind projects, and participating early intervention programs. This video was completed too late for feedback from the field.

In addition to feedback from the dissemination process, the first three videotapes and manuscripts of the project manual were reviewed by 6 national reviewers in different states across the counrty. These individuals were direct service providers, consultants, and program administrators in early intervention programs serving infants who are deaf-blind and their families. Feedback from the national reviewers was used to refine the manuscripts for the project manual and to develop the booklets for the videotapes.

Project Impact

The project has had immediate effect on the infants who are deaf-blind and their families by building the capacity of their early intervention programs. Moreover, the early intervention staff and programs who participated in the project are now more skilled in serving this population in the future. Project procedures and materials were field tested and disseminated nationally during the last two years. It seems likely that this widespread dissemination has influenced

intervention practices in other programs as well. Moreover, it is anticipated that widespread and long lasting effect on the field of early intervention for infants with multiple disabilities/vision and hearing loss through continued dissemination of the project videos and manual.

Dissemination activities involve presentations at a number of state and national conferences across the three years:

March 1995- California Transcribers and Educators of the Visually Handicapped (CTEVH) Conference in Santa Clara, California

October 1995 - Divison for Early Childhood Conference, Orlando, Florida

March 1996 - California Transcribers and Educators of the Visually Handicapped (CTEVH) Conference, San Diego, CA

July 1996 - Association for the Education and Rehabilitation of Persons with Visual Impairments (AER) Conference, St. Louis, MO.

December 1996 - The National Conference of Association for Persons with Severe Disabilities, New Orleans

January 1997 - The Infant Development Association Conference, Irvine, CA

Regional workshops:

February 1995 - Functional Hearing Screening for 25 school nurses serving special education programs for children with severe and profound disabilities, Los Angeles County Office of Education

October 1996 - Southern California Infant/Preschool Field Meetings, California

Department of Education, Anaheim, CA.

January 1996 - Interagency Coordinating Council, San Bernardino County

Products include a manual and four videotapes with accompanying booklets. The project disseminated a total of 475 copies of the four videos and 200 copies of the manual. Participating early intervention programs, selected inservice and preservice programs, all 307.11, and some other deaf-blind projects received a complimentary copy of the project manual, each video, and a draft of one booklet. The booklets for all four videos were developed based on input from field reviewers and the 307.11 projects. All four videos are closed captioned and *Making the Most of Early Communication* is audio described as well.The videos will disseminated by commercial publishers as follows:

What can baby hear? Auditory Tests and Interventions for Infants with Multiple Disabilities (27 minutes*)*. Paul H. Brookes Publishing, P.O. Box 10624, Baltimore, MD 21285. This video identifies the importance of early identification of hearing loss particularly in infants with severe and multiple disabilities. An pediatric audiologist demonstrates selected audiological tests (Behavioral Observation Audiometry, Visual Reinforcement Audiometry, Auditory Brainstem Response, Otoacoustic Emissions) for infants (under 24 months). Shows an early interventionist obtaining functional hearing information with an infant who has both vision and hearing loss through structured observation in the home and parent interview. The mothers and early interventionists of three other infants with

different types of hearing loss discuss their infants' listening and communication skills. Shows selected strategies in an total communication early intervention program and emphasizes the consistent use of hearing aids. Includes a booklet.

Making the Most of Early Communication (34 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. This video emphasizes the importance of making use of the child's available senses, using familiar routines and turntaking games, and using systematic and direct instruction for encouraging communication. Shows various communication strategies (oral and total communication, touch and object cues) with a variety of infants, toddlers, and preschoolers with multiple disabilities/vision and hearing loss at home and in preschool activities. Children from five different programs are shown. Includes a booklet.

What can baby see? Vision Tests and Interventions for Infants with Multiple Disabilities (30 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. This video identifies the importance of early identification of visual impairment in infants with severe and multiple disabilities. A pediatric optometrist demonstrates five common vision tests (checking ocular health, Cover-Uncover Test; Pupillary Response, Retinoscopy, Preferential Looking/Teller Cards, and the Visual Evoked Potential). Shows an early interventionist obtaining functional vision information with two infants who have both visual impairment and hearing loss through structured observation in the

home and parent interview. Parents share their feelings about their infants' disabilities. Provides examples of selected interventions used in an infant program. Includes a booklet.

Vision Tests for Infants (20 minutes). AFB Press, American Foundation for the Blind, Eleven Penn Plaza, New York, NY 10001. A pediatric optometrist demonstrates a comprehensive battery of vision tests that are appropriate for infants under 12 months of age. These tests include: Versions, Hirshberg, Krimsky, Unilateral and Alternating Cover, and Base out Prism (fixation and eye alignment tests); Pupillary Response; Vestibular Ocular Reflex; Retinoscopy; Contrast Sensitivity, Color Vision, Depth Perception, Visual Field, and Visual Acuity (behavioral tests); Visual Evoked Potential and Electroretinography (Electrophysiological tests); and checking ocular health. Includes a booklet.

In addition, the project produced a manual entitled *Effective Practices in early Intervention. Infants whose multiple disabilities include both vision and hearing loss* that documents the training topics, effective practices, and key strategies developed and identified by the project process. Chapters were contributed by project staff and consultants who provided technical assistance to programs, workshops, and appeared on the videos. Topics include:

Program Self Review: A program development process

Mentorship and collegial support: Enhancing the early intervention team

The art of collaboration

Identifying infants who are deaf-blind

Strategies for gathering information

Functional vision assessment and interventions

An easy guide to tests used to diagnose visual impairments in infants

Clinical vision assessments for infants with severe and multiple disabilities

Gross motor development in infants with multiple disabilities

Understanding medications and medical interventions

Beginning communication

Infant vignettes

From interdisciplinary to transdisciplinary interventions

Off to preschool! A parent's perspective

Planning transitions to preschool

Educating young children with severe and multiple disabilities in typical preschool settings

AFB Press has expressed an interest in publishing some of the chapters of the project manual and the Project Director will work on expanding and revising the selected content for publication during the summer.

Additional information is contained in the project manual. This final report and project manual is being sent to ERIC/EECE, Children's Research Center, University of Illinois, 51 Gerty Drive, Champaign, IL 61820-7469